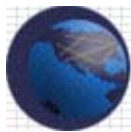




Data Sharing and Intellectual Capital Working Group Teleconference

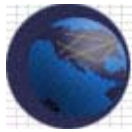
April 29th, 2004	2:00 pm EDT
Attendees:	<p>City of Hope National Medical Center and Beckman Research Institute: Joyce Niland</p> <p>University of Iowa-Holden Comprehensive Cancer Center: Tom Cassavant; Terry Braun</p> <p>The Jackson Laboratory: Janan Eppig</p> <p>University of Minnesota Cancer Center: Don Connelly</p> <p>Washington University-Siteman Cancer Center: Mark Watson</p> <p>OHSU Cancer Institute: Shannon McWeeney; Vincent Yau</p> <p>Fox Chase Cancer Center: Pat Harsche-Weeks</p> <p>University of Pittsburgh Cancer Institute: Michael Becich</p> <p>Fred Hutchinson Cancer Research Center: Robert Robbins</p> <p>NCI: Wendy Patterson; Leslie Derr</p> <p>Booz Allen Hamilton: Phan Winter; Theo Wills</p>
Introduction	<p>Wendy introduced the meeting and stated that the agenda would cover administrative matters. The Group was asked whether they had any comments to the notes from April 16th meeting. One participant thought that the notes suggested that Denise was going to call each Center's POC. Phan explained that Denise is in the process of contacting each Center's contracting POC. The Group concluded that the notes were accurate and could be finalized.</p>
DSIC Working Group Liaisons	<p>The following liaisons were established:</p> <p>Architecture: Robert Robbins (primary); Vincent Yau</p> <p>Training: Ed Quick (primary); Michael Becich</p> <p>Strategic Planning: Michael Becich</p> <p>Integrative Cancer Research: Tom Cassavant; Terry Braun</p> <p>Clinical Trials: Don Connelly</p> <p>Vocabulary and Common Data Elements: Michael Becich</p> <p>Tissue Banks and Pathology Tools: Mark Watson</p>



	<p>Liaisons will report back concerns identified by other Workspaces and Working Groups at the beginning of subsequent meetings.</p>
Status of Open Action Items	<p><u>IP Contacts</u></p> <p>All DSIC participating centers should provide IP contact information to Phan. The IP POC should be a person who is familiar with issues relating to data sharing and intellectual property.</p> <p>Don Connelly requested that a brief statement describing the caBIG project and the role of the IP contact in caBIG be drafted to aid in soliciting IP POC assistance from the tech transfer office. Pat Harsche-Weeks recommended that DSIC WG members inform their IP POCs that they will be consulted on an ad hoc basis for their general views and insights and will not be asked to negotiate individual contracts.</p> <p>Wendy will draft a paragraph that DSIC Working Group members can forward to their IP POCs when approaching them to participate in the caBIG project. When this introductory document is ready, Phan will email it to DSIC WG members and also set up a link to the DSIC online forum for convenient access.</p> <p><u>Teleconference schedule</u></p> <p>The Group was asked whether a bi-weekly schedule is reasonable. The consensus was that this schedule is necessary to keep the project moving, especially at the early stage. The Group generally agreed that the default schedule of meeting bi-weekly should stand and that specific meetings will be cancelled as the need arises.</p> <p>One Group member suggested that specific DSIC participants be assigned tasks that can be tracked at subsequent meetings. Phan responded that BAH is already tracking these activities by using the action items at end of the notes for each meeting.</p> <p><u>Questionnaire</u></p> <p>Pat Harsche-Weeks and Wendy will have a conference call next week to discuss the survey development. Following this discussion, a draft questionnaire will be posted to the DSIC</p>



	online forum for comment by DSIC WG participants.
Formation of Advisory Group to DSIC Working Group	<p>The Group continued the discussion from the last meeting concerning the formation of an advisory group to the DSIC WG. Wendy suggested that the paragraph she is preparing for the tech transfer offices might also be appropriate for introducing advisory group members to the caBIG project and their proposed role in the DSIC Working Group. After a brief discussion, the Group agreed that members of the advisory group would participate on an ad hoc basis, when there were specific agenda items relevant to their area of expertise.</p> <p>Pat Harsche-Weeks stated that pharma/biotech participants and academic institutions hold very different views on the value data which affect their willingness to share. Therefore, she recommended that industry be consulted as the DSIC WG moves forward in developing the questionnaire so that the document will solicit information in a realistic manner. Pat reported that she had spoken with a representative from Celera Genomics who indicated that the company has general interest in providing input to the caBIG project and will identify someone from the company who would be willing to participate. Pat also suggested that the DSIC WG seeks input from companies operating tissue banks and repositories. She thought that Ardaís Corporation would be a helpful resource and offered to contact Martin Ferguson, the company's director of bioinformatics, within the following week. It was suggested that industry representatives be engaged in providing real time feedback on the questionnaire during the teleconference on June 10.</p>



Agenda Items for Next Meeting

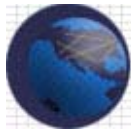
The Group agreed to skip the next scheduled meeting set for May 13th since Wendy will not be available to attend and there are no urgent business items. Therefore the next meeting will take place May 27. The Group discussed agenda items for the next meeting.

Bob Robbins would like to follow up on the discussion regarding the goals of data sharing. He stated that the DSIC WG should recognize that data sharing within the research community typically occurs at the following different levels of sharing:

- No sharing at all
- Sharing restricted to active collaborators
- Limited sharing within a broader research community (e.g., the NCI's Early Detection Research Network (EDRN))
- Open data sharing without any restrictions (e.g., data are accessible through a website)

Bob stressed the importance of making sure that we consider this hierarchy for sharing data and software and that both academic and industry members of the research community use the same definitions of data sharing and of clarifying whether these definitions apply equally to: tissues; reagents; software source code; and data produced from the use of software programs. In this regard he noted that it is important to recognize that there are different views as to the value of data, the willingness to share data, and the different norms as to what constitutes acceptable levels of data sharing. In evaluating these issues, it will be important to understand whether the monetary value derives from the data or the software program.

Bob noted that notwithstanding expectations for ideal sharing arrangements, other factors may influence the way that data sharing occurs in actual practice. Relationships between researchers, which are based on individual personalities, frequently drive the way data are shared. In addition, other factors may contribute such as the fact that raw data is messy and the researcher being asked to share may not have time to clean up the data. In view of the risk of errors associated with getting data out quickly, it is not unreasonable to allow researchers some time before requiring them to make the



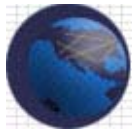
primary data available.

The Group discussed the fact that research community norms are in the process of evolving from a model of viewing data as objects to protect, to a model of an open information framework in which data is a commodity. Members of the Group observed that data sharing standards for the research community are currently at the interface of these models. Bob Robbins credited the funders of the GenBank project with the social re-engineering of scientific attitudes toward data sharing over the last twenty years. He also recommended "The Genome War" by James Shreeve, which chronicles the race to sequence the human genome, as a good book to read on the issues of data sharing.

Wendy offered to provide a summary of approaches to data sharing utilized in various NIH initiatives such as the "glue" grants funded by NIGMS and the Biomedical Informatics Research Network (BIRN) funded by NCRR. The Group suggested that she also focus on NCI initiatives such as the SPORes, which should be tapped for the survey. Many of the SPORes already have repositories with multi-site collaborations in progress. Some members of the Group conjectured that some issues about data sharing may already have been worked out and should be explored. One member pointed out, however, that standards may have been written, but not implemented as planned. Therefore, the DSIC WG may want to invite representatives from such initiatives to understand better the challenges in implementing data sharing standards. The Group concluded that soliciting input from disparate groups would provide the full spectrum of challenges.

Action Items:

Name Responsible	Action Item	Date Due	Notes
Pat Harsche-Weeks	Call Martin Ferguson at Ardaïs	5/07/04	
	Contact Celera	5/21/04	
All	IP contact	5/21/2004	



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	Wendy	Brief statement of role for IP POCs	5/07/2004	
	Pat Harsche-Weeks	Planning questionnaire – due diligence	5/06/2004	Discuss questionnaire with Wendy
	Wendy	Brief statement of role for advisory group participant	5/14/2004	
	Wendy	Drafting approaches to sharing based on NIH grants	6/10/2004	
	Phan	Send out statement for IP POCs to Centers and post on Forum	5/10/2004	Pending internal reviews
	Phan	Send out statement for advisory group participant to Centers and post on Forum	5/17/2004	Pending internal reviews
	Various	Invite industry representatives to provide feedback on questionnaire during the teleconference on June 10	6/3/2004	Pending group discussion on 5/27/04